

Fairer access to care and benefits for terminally ill people in the UK

We're calling on all UK political parties to pledge to:

Scrap the six-month rule that obstructs terminally ill people from gaining access to benefits unless they can prove they only have six months left to live.

Offer free personal care to everyone with a terminal illness, regardless of their age or finances.

In the next 10 years, more than six million people will die in the UK. Of this number 75% will need palliative care. Our NHS is already under extreme pressure, particularly in emergency departments, where nearly 30% of admissions are for people in the last year of life, at a cost of £2bn annually.

Based on current projections England alone will need 4,000 extra beds by 2041 and another £1.6bn just to maintain the status quo. Many emergency admissions are preventable. Our two proposals for the next government will help keep people with a terminal illness out of hospital unless they have a real clinical need to be there and help keep our NHS sustainable.

Rationale

Caring for people with a terminal illness in hospital is costly. Often, the person will have no real clinical need or desire to be in hospital but will have ended up there because of an emergency admission that could have been avoided. Too often, these people then struggle to leave hospital

because of insufficient care in the community. Unfairly, these people will often be labelled as 'bed-blockers'.

This is a critical issue for the NHS. Nearly one-third of emergency hospital admissions are for people at the end of life. Reducing this figure must be a

priority for the next government to ensure that the NHS is sustainable and is able to deliver timely emergency care to people who need it in the future.

Our two proposals will help achieve this.



Scrap the six-month rule

People living with a terminal illness are estimated to be around £12,000 - £16,000 worse off per year after receiving their diagnosis. This is a severe hit for many families. It not only causes stress and anxiety while they're coming to terms with the devastating impact of a terminal diagnosis, but can also make things like adequate food and heating unaffordable.

The benefits system is meant to cushion terminally ill people against this situation. However, the current rule, which requires them to prove they have six-months left to live to get fast track access to benefits, means many people are missing out on the support they need, or facing waits as long as 16 weeks and huge amounts of red tape to get financial support. Cases where the Department for Work and Pensions (DWP) is still contesting a claim after the person has died are not uncommon.

The six-month rule has no clinical or scientific basis – most doctors and nurses oppose it and think it's inhumane. By removing the six-month rule

from the statute books, and instead trusting doctors and nurses to use their judgement about when someone is terminally ill, the next government can make a huge impact on the lives of terminally ill people at minimal cost.

“My benefits were stopped because my cancer didn't give me the right number of points to get any benefit. I was told that they did not contact doctors or hospitals for medical details”

With proper access to benefits, people are better able to heat their homes, afford the food they need and make the adaptations to their home that can help them keep out of hospital at the end of life. A small additional spend in the welfare budget has the potential to deliver huge savings for the NHS.

Free personal care at the end of life

One of the key reasons that people in the last year of life experience so many emergency admissions is because there's not enough provision of personal care in the community. Once they're in hospital, that same

shortage of care can keep them there, often until they are too ill to be moved.

This makes no sense. Research has consistently shown that providing people at the end of life with high quality social care is cheaper, reduces the need for emergency care, and eases pressure on hospitals. While the cost of hospital care rises the closer someone is to death and with the number of conditions that person has, social care costs remain stable.

“When my mum needed the help from the state to pay for her care the most, her hours were cut. A woman who had paid into the system for so long and changed so many peoples' lives was left to live in poverty.”

Making personal care free for people with a terminal illness is an easy fix for the next government. It costs less than hospital care, it keeps people out of hospital unless they have a real clinical need to be there, and it'll go a long way to easing pressure on overstretched emergency departments.

“It was awful. More help was needed for some time but no care was offered. He was in hospital for a month, six weeks before he died. He needed a lot of nursing as a result of his undiagnosed dementia. There was still no care package on leaving. A week before he died we were still pleading for an assessment but told he wasn’t ill enough.”

About Marie Curie

Marie Curie is the UK’s leading charity for people affected by terminal illness. We deliver palliative and end of life care to people across the UK in their own homes or in our nine hospices. We also run an information and support service which offers help and support to terminally ill people and their loved ones.

We are also the largest charitable funder of palliative and end of life care research in the UK. We campaign to improve access

to and the quality of palliative and end of life care and we provide the secretariat to the All-Party Parliamentary Group for Terminal Illness.

Our ambition for the UK is that everybody can access high-quality palliative and social care at the end of their lives regardless of their personal circumstances, that everybody living with a terminal illness gets the financial support they need, and no-one spends the final

days of their lives in unnecessary pain and distress. To deliver on this ambition, it’s vital that end of life care and social care receive the priority they deserve.

For more information

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